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SPEAKERS

Christine Chaikin, Steve Barclay, Tom Frank, Rob Mineault, Ryan Fleury

R

Rob Mineault 00:08

Hey, welcome to another episode of AT Banter.

S

Steve Barclay 00:25

Banter, banter.

R

Rob Mineault 00:37

Hey, this is of course the podcast where we talk with advocates and members of the disability community to educate and inspire better conversation about disability. Hey, my name is Rob Mineault. And joining me today, Mr. Steve Barclay.

S

Steve Barclay 00:55

Yay, it's me.

R

Rob Mineault 00:57

Yeah. So we missed you so much after you've been away for so many weeks that I'm giving you top billing again this week.

S

Steve Barclay 01:03

Excellent.

 Rob Mineault 01:15

And hey, look who else it is. It's Mr. Ryan Fleury.

 Ryan Fleury 01:18

Hey, it's Ryan Fleury. Hello everyone.

 Rob Mineault 01:22

And no Lis Malone today. Sadly, she's got other and other engagement. So you'll just have to put up with the boys today.

 Ryan Fleury 01:32

I think the IRS is looking into her.

 Rob Mineault 01:35

Yeah, I heard I hear she was getting audited. I guess that's the downside of being an LLC is that you get those audits. So how are you guys?

 Steve Barclay 01:49

I'm just dandy.

 Rob Mineault 01:51

You're always dandy.

 Steve Barclay 01:57

Well, I'm okay.

 Rob Mineault 02:00

That's better.

 Ryan Fleury 02:01

Did the Canucks win last night?

 Steve Barclay 02:03

They did.

 Ryan Fleury 02:04

That's why he's dandy.

 Rob Mineault 02:05

Are they still so they're still doing quite well then?

 Steve Barclay 02:09

Yeah, they're still top of the Pacific Division. So so long as we win our next few games and beat Edmonton the one time that we play them, we'll finish in top spot in the Pacific Division with home ice advantage.

 Ryan Fleury 02:33

And the playoffs are starting the week and a half.

 Steve Barclay 02:37

Yeah, it's coming up fast.

 Rob Mineault 02:40

I smell a riot.

 Ryan Fleury 02:46

Oh, it could happen. Yeah.

 Rob Mineault 02:48

I'm excited for all those the Canucks fans out there, I feel like this is overdue, because when when was that last riot? Where we made the playoffs and then got knocked out? Was 2011?

S Steve Barclay 03:07

It was 2011, yeah.

R Rob Mineault 03:08

it's like 10 years. So we are due to at least get into the playoffs, right?

S Steve Barclay 03:13

Absolutely.

R Ryan Fleury 03:15

Yeah, well, we're in the playoffs.

S Steve Barclay 03:17

I think we are definitely in the playoffs. hook or by crook.

R Rob Mineault 03:21

That's great. That's awesome. Well, good. I'm glad. Do you still have that thing in your living room? That little hockey siren that goes off whenever they score a goal?

S Steve Barclay 03:34

No, it got put away one Christmas and it's never been seen since. Jackie finally got sick of it. Well, this isn't the time to put somewhere safe.

R Rob Mineault 03:45

You should you should do some research and pull it out of mothballs because you don't know you know you might be might be useful going into playoffs. Well, listen, I'm going to I'm going to end our little banter fest because I feel like it's that's ending on a positive note. Hey, Ryan. Yeah, Rob? What are we doing today?

R Ryan Fleury 04:15

Today we are speaking with Christine Chaikin and Tom Frank from the Council of Citizens With

Low Vision International. Hello, folks, thanks for joining us.

 Christine Chaikin 04:25

Well, thanks for having us on.

 Ryan Fleury 04:28

Thanks, Christine. I hope I pronounced your last name correctly.

 Christine Chaikin 04:32

Yes, thank you.

 Ryan Fleury 04:33

Good.

 Rob Mineault 04:34

You're getting better at that.

 Ryan Fleury 04:35

It's only been nine years.

 Rob Mineault 04:39

Right? You'll get there. Something to try for the 12th year anniversary. No, listen, we are very happy to have you guys on the show. Maybe we can just start out with one to maybe can just give us sort of a bird's eye view of the organization and what you do, and maybe each of you could just let us know what each of you does at the organization.

 Christine Chaikin 05:06

My name is Christine, and I'm a member of the Publications Committee, as well as the Public Relations committee. CCLVI is a 501 C three nonprofit organization. It is a special interest affiliate of the American Council of the Blind. Basically, it's those people who have low vision. Also Dr. Sam Genensky, was one of the founding members of CCLVI as well as the inventor of the CCTV.

T

Tom Frank 05:39

He's one of the ones that started it. CCLVI. We always say the Council of Citizens with Low vision International, and I think the international because we had one or two Canadians and maybe somebody from New Zealand on there. Yeah, basically, we deal with low vision. And of course Genensky he invented the CCTV. And I 1979 is when the organization started. And I got my first CCTV when my vision started going bad while I was in the army at age 20. Now that would have been around 1970. Boy, that's a long, long time ago. And I sort of struggled with low vision, I could sort of read the textbooks with a small print, but I was having more problems and more problems. And I started out as a chemistry physics major wanted to teach high school physics. But when I got to the point where I could no longer read the labels in Chem lab and though I think I'd want to change majors before I blow myself and everybody else up. So I changed to advertising public relations. And now I'm chair of the Public Relations Committee for CCLVI, but I struggled until 1973 when I medically retired from the army. So I went to the Veterans Administration here and, and West Haven, Connecticut, one of the original blind rehab centers, or the Veterans Administration, and I got a CCTV way back in 1973. And with that technology, I made it through college, grad school, worked in Washington, DC Blind Veterans Association, and doing a lot of things with that CCTV until my vision got bad enough so that didn't really work. And fortunately, the iPhone came along with talking computers and iPhones. So I made the transition. And that's one of the major things that we help people do is deal with their low vision no matter where they are. And I'll let Christine say how we do that.

C

Christine Chaikin 08:15

So there are several different events that CCLVI has. On Mondays, we have a general chat topic. The second Monday we have CCLVI game night. Third Monday is low vision support group. And then first Thursday is our Let's Talk Low Vision and this is basically different people in the field. We've had people from the different Lighthouses, like low vision specialists and they talk about different products that they sell on Lighthouse. CCLVI also has five different CCLVI chapter affiliates, which are the California Council of Citizens with Low Vision, Delaware Valley Council of Citizens with Low Vision, Florida Council of Citizens with Low Vision, Kentucky Council of Citizens with Low Vision and New York State Council of Citizens with Low Vision.

T

Tom Frank 09:22

And I'll say Delaware Valley for those of you from Vancouver or wherever, the Delaware Valley includes the States of Delaware, Southern New Jersey, where I'm from originally and eastern Pennsylvania. So you know what the, they have their own meetings, but they're an affiliate of us and we are an affiliate of the American Council of the Blind. an

C

Christine Chaikin 09:45

Special interest affiliate.

S

Steve Barclay 09:47

What exactly does that mean, a special interest affiliate?

 Christine Chaikin 09:50

So basically what that means is special interest affiliate. It's like under the umbrella of the American Council of the Blind. So American Council of the Blind has two different things. One is the state affiliates, where each state can have ACB chapter. But most states don't have them, but a lot of them do. And then ACB also has special interest affiliates. And when you become a member of one of those special interest affiliates, such as the CCLVI, you automatically become a member of the American Council of the Blind, as well.

 Tom Frank 10:24

As some of the other Special Interest Affiliates, blind lawyers, blind teachers, blind Information Technology Specialist. People interested, more advanced in the technology...

 Christine Chaikin 10:41

Then you got the visually impaired attorneys, too.

 Tom Frank 10:44

And yeah, so you have a whole variety of special interest groups, families, students, for the younger members ..

 Christine Chaikin 10:55

Students, they used to be next generation.

 10:58

So you know, whatever, wherever you are, you know, there's a affiliate that sort of meets your little, little group, your cliche, or whatever you want to call it.

 Rob Mineault 11:13

So now, how old is the organization?

 Christine Chaikin 11:15

It was founded in 1979. So it's 45 years, they believe?

R

Rob Mineault 11:21

Yeah, I'm terrible at math, but sounds good to me. 45. So in terms of membership, you're based on those five chapters, sort of depending on where you are in the country, you would sort of fall into each of those zones?

C

Christine Chaikin 11:36

Basically how that works is if you're in the state of California, you can join one of those that California Council citizens. If you happen to be in a state where, you know, CCLVI doesn't have a chapter or CCLVI chapter affiliate, you can also become a member at large, which means you don't belong to a ACB chapter or you don't belong to a CCLVI chapter affiliate. So that's where members at large comes in.

T

Tom Frank 12:06

Yeah, same thing with the American Council of the Blind. Like Vermont, we have the Vermont Council of the Blind, but some states may not have a state affiliate, but they can still join ACB as a general member at large.

R

Rob Mineault 12:24

What I find really interesting about the organization is, is that it's specifically tailored towards low vision. I feel like there there are a lot of organizations that are blindness organizations. And low vision is, is a little bit of its own animal when it comes to the disability community. Can you talk to us a little bit about, say, the origins of the organization and why it was kind of founded and kind of some of the important tenants that that you guys are advocating for?

T

Tom Frank 12:55

I'll say, I think you hit the nail on the head there, that when it was started, and I go way back to 73 went to the IBA, and I was sitting with the director of the Blind Center, and he was a World War Two guy who had lost his vision during World War Two. And one of the founding members of the BVA the Blinded Veterans of America. And, you know, he sat down, he was totally blind. And he said, you know, you low vision guys, a lot of us don't know what to do with you. You're neither fish nor fowl. You're not blind and you're not sighted. We don't know what to do with you. And then, even today, folks will go to an optometrist, or an ophthalmologist, and their vision is 2100 in the right eye, and one even 200 in the left eye, or they have glaucoma and a field loss. And they'll do certain things. But then they'll say, you know, there's nothing that can be done. And that couldn't be further from the truth. What they mean to say or should say is, there's nothing I can do for you, medically, what vision you've lost, but that doesn't mean there isn't anything, there's lots of things that can be done. And that's what we do. We help, through our chat sessions and support and our resource page on our website CCLVI.org,

we help people understand that. Yeah, you can't drive a car now but no, your life did not end. You know, there's now there's Lyft, there's Uber. Yeah, so if you live in the middle of nowhere, you'll be able to travel. And I used to hitchhike everywhere, you know, I would get where I needed to go. But I'm sort of a rare breed and that out, I'll get where I want to go somehow. You know, public transportation. And when I lived in Southern New Jersey, which was rural, it was hard. And, you know, other low vision, people understand, you're not the only one - other people are doing this, as well. And then I moved to Washington, DC. And there's subways and buses, and it really didn't make much of a difference. But you know, how you can deal with that low vision, and, you know, support each other and do absolutely, as much as you can do. Don't give up? Yeah, jump in, do it, do it, get yourself a white cane. But just talking to somebody about using the white cane, like, I don't want to use a white cane. People are staring at me. And you've probably heard people say that. And my response to that is, but uh, why do you you care, you can't see them? They're staring at you but wait until you step into that manhole and disappear. Then there'll be staring at you.

R

Rob Mineault 16:43

Very true. Well, you know, the, the other interesting thing about this is that for many people, especially who may be getting some sort of degenerative eye condition diagnoses, and is working through that. They may be low vision, or and they may be part of that low vision community, on the way to say, becoming a member of the blindness community. So, you know, there's a, it's almost like an entry point for some people as well.

T

Tom Frank 17:17

And we have members that are totally blind, and they went through that transition, and they can help. It isn't the end of the world for them, either. And, for some people, the folks that we deal with, it's a real struggle. If you're blind, you can't see. You learn braille, you learn your mobility. But tomorrow, guess what, you're still blind, nothing has really changed. Low vision, every day that you get up, thinks could be a little different. And how do you adjust, you've adjusted perfectly well, and then your vision gets a little worse. And now you got to readjust and readjust. And these are the things that we you know, there's other people, we've all gone through it, or you'll find somebody just like you that can help.

R

Rob Mineault 18:14

Yeah, well, that's why I you know, I my ears perked up when you when, when you mentioned your peer support group, because I do feel like that is a really a really huge component to helping people in that transition process. Because for people who are coming out a diagnosis and their their vision is changing, even even if it's rapid I mean, there is going to be a point where they may be more low vision than blind at that moment. And being a new thing for them, that peer support and be really super integral. Can you talk to me a little bit about about the peer support group, specifically the kind of things that you try to help people through?

C

Christine Chaikin 19:00

So basically, every third Monday. How that works as a peer support group is a call where they

So basically, every third Monday. How that works as a peer support group is a cup, where they have different people, like they have a group of people come on and talk about maybe tips and tricks or maybe about assistive technology. How do you know when your cup is overflowing? You know, basically tips and tricks of how to help other people do different tasks.

R

Rob Mineault 19:25

The assistive technology component is important too, because, you know, the three of us have worked in and currently work in the assistive technology field. And, you know, one of the things that always seems to come up about assistive technology, people don't really know anything about it until you know the day that they need it. So for a lot of people who are just coming into this and are just starting to be entering into the low vision community, they don't always really know even what what's available to them and when what they're still able to do with the right adaptations.

T

Tom Frank 20:02

And once again, the low vision part of it, as opposed to blind. If you learn braille as a child, and you're proficient at Braille or whatever, that's great, that's wonderful. And depending on where point you might want to learn braille, but you get somebody that's 50 or 60, and one of the leading causes of new blindness is age related macular degeneration, and that person might be 60, 70, 80. Let's face it, they're not going to learn braille. And you know, I do work with Vermont Associates for the Blind which is State agency. And we provide training and all of that as well. You can you start with oh, well, you'll get the iPhone, and that can talk to you. But they're not there yet. And so technology, dealing with people where they are, and other peers that can help them, for example, our organization, we went around and trained not through CCLVI, but that's what I know. And talking to a woman who's she's in her 70s, and what did she want to use her vision for an iPad so she could talk to her grandchildren in California. That's all she wanted. And that made her day. And anything else we tried to teach her she wasn't really interested. And we had a little very, very complicated technology if you go back 20, but a little, you know, Amazon, the little dots, Echo dots, you can buy them on sale now for 20 bucks, 30 bucks, using Alexa. And she was having all sorts of problems using the voiceover the screen technology on the iPhone, so brought in her an Echo Dot and set that up for her. And there it, we taught her one or two things to do with it went back two weeks later, and she said come on over here, come here, sit here on the couch, sit here and watch. "Alexa, play Frank Sinatra". And it started playing Frank Sinatra and she was as happy as could be. So the technology for blind, although the technology be may be complicated, all the the use and the different software and all that is getting much much better for a lot people to use.

R

Rob Mineault 22:58

Yeah, for sure. Well, I mean, I mean, there are manufacturers out there that specifically make their products friendlier for, say an old an older demographic specifically for that reason, because, you know, they understand that, you know, they're their main demographic that's going to be say using this device is going to be tend to be people who are going through something like age, age related macular degeneration, and the user interface on their particular product needs to be dialed down.

T

Tom Frank 23:31

And that's what we emphasize when we talk to folks and offer support on you know, the third Monday, eight o'clock Eastern time. But it's nationwide. And Christine, I don't know where you are now, but Christine is from Hawaii. So, all I know is I don't call Christina at nine o'clock in the morning because it's three o'clock her time. And vice versa.

C

Christine Chaikin 24:02

If you want I can talk about some of the committees that CCLVI has. Yeah, so some of those committees include we have a total of a lot of them, but I will only cover a few of them because if I cover all of them, you'll be overwhelmed. One of them is the Public Publications, which is a committee that puts out a newsletter called Vision Access, which comes out six times a year. It is available in email and in large print hardcopy. You can also we are always looking for content for Vision Access. So in the maximum word count is 500 words. If anyone is interested in submitting content to Vision Access, you can send that to cclvivisionaccess@gmail.com. Another committee that we have is the Public Relations and basically what that committee does is we help get the word out, like such as being on different podcasts and getting the word about CCLVI, we also put a flyer out that gives you more information about CCLVI. And I can also include that in the email when I send it with the show notes. If people have questions about CCLVI, or questions about the Public Relations Committee, you can send an email to lowvisionoutreach@gmail.com. And then the other one I'm going to cover is the Scholarship Committee. And basically what that one is, is, is where they give out \$3,000 scholarships to incoming freshmen, graduate, and undergraduate. And so if anyone is interested, like if you're in high school, college, that usually starts up on January 1 of every year. So if anybody wants to, you know, check that out for next year. You can go to cclvi.org/scholarship. As Tom referred to, there are several categories. And the direct link to that is cclvi.org/resources. And I'm sure people are going to ask how can I tell what kind of articles you guys have on Vision Access? Well, you can go to cclvi.org/visionaccess.

R

Ryan Fleury 26:33

Your website talks about CCLVI being an advocacy organization, reaching out to external entities, helping people maximize and utilize the vision they have, educating the public, looking at research initiatives to prevent blindness, so on and so forth. So what does advocacy look like at CCLVI? And what are some of the projects you guys are working on?

T

Tom Frank 27:01

I'll say one of the one things when Christina mentioned that we put our newsletter out also in large print. Me personally, I like to get mine on an email. Because large print, you know, two feet high as a little large, very large paper, you have to print that on now, but to advocate ACB and our own parent organization wasn't necessarily making all of their printed material in large print. So we advocated internally to come up with standards. You know, what color text or what color background what size it needed to be, what font, and then also advocating to other agencies like the head of the Library of Congress, the National Library Service, which does the

Talking Book programs, by making sure or the audible books on on tape, we always say on tape, but there actually now all digital. Making sure when they put out printed material, it's available in large print, advocating for large print books. And other because especially once again, older folks as they're losing, they like to hold a book, they always held a book, and they still can get it in large print a lot of novels. Hey, the Reader's Digest in large print. So we're advocating for those and Christine can think of some others.

C

Christine Chaikin 28:53

The other thing they advocate for is like trying to get like insurance paid to pay for like devices and stuff.

T

Tom Frank 29:01

In Canada, Canada pays for everything right? ,

R

Rob Mineault 29:04

God, we wish.

T

Tom Frank 29:07

Oh, boy, do I have a fella from Montreal and he's always saying but so and so won't pay for it. What's your main I forget what your main agency?

S

Steve Barclay 29:20

CNIB is the only national blindness organization agency.

R

Rob Mineault 29:30

Yeah. Our funding is messed up too.

S

Steve Barclay 29:33

Yeah, it's all it's all provincially based, there's no there's no national funding. It's all province by province. So Ontario and Quebec have programs but the rest of the country that has very limited access to technology.

T

Tom Frank 29:47

Ah, okay. And so while we have in one way, we have Medicare, which is everything but

Medicare doesn't pay for glasses and most Vision Services, but Medicaid for people who are low income, or over age 65, Medicaid and their low income as well pays for other things. And one thing they do, and that varies from State to State as well, I know here in Vermont, if you're on Medicaid, and you need a CCTV, they will pay for one, but as limit to \$1,450. So, you know, it's not definitely not the Cadillac, but it's better than nothing. So CCLVI, helps our members, you know, advocates to our members to advocate within their states. And then, of course, those affiliates, the five affiliates that Christine mentioned, also go, to the state affiliates, their own state governments, like your provincial governments to provide various technologies and training. And in the States, that really varies widely. Like in Canada, I would assume what you get in Nova Scotia is don't what you get in Alberta.

R

Rob Mineault 31:17

Correct. That's right. And, you know, it used to be it used to be better. I mean, there were there were more provinces that that had some some funding. Steve, wasn't Alberta for a while pretty, pretty good?

S

Steve Barclay 31:33

Well, Alberta still has a program. They've got the STEP program out there that's administered by by CNIB, but it's it's a limited pot of money, and you know, they get so much money each year, once it's gone, that's it.

T

Tom Frank 31:44

Yeah. Edmonton in Alberta. And actually the person that we talked to a lot in Montreal complaining about services here in Montreal, was from Edmonton and said, I got a lot more in Edmonton. And he would say they had a lot of services, Edmonton. So there's Alberta. So. And, once again, that's the thing. You know, we advocate, though, what is Medicare going to pay for? And, and, of course, we support we're members of ACB. And a lot of ACB really advocates a lot and lobbies, you know, the federal legislature. And ACB, I'll also say has an office outside of Washington, DC, and lobbying efforts, making sure we have funding from the Older Americans Act, and also helping individuals, you know, that are that our members and on our support calls, who you need to call, you know, encouraging people. You've got to stand up for yourself as well and try to get their esteem back. You know, what happens if I apply and they say no? And I was used to be a Claims Representative retire claims representative from Social Security. And people would say, like, they probably say in Canada, if I apply for disability, they'll deny? And my answer would be, if you apply actually, about 50% of them are approved the first time. So if you apply, I have no idea if you're going to be approved. But if you don't apply, I guarantee you won't be approved. So if you don't ask for services from British Columbia, you're not going to get any. We are CCLVI, international - the I is international. So make the same recommendations to folks in BC and Alberta and Saskatchewan ... and you're probably shocked I know those promises, right?

S

Steve Barclay 34:27

But can you name them all?

But can you name them all?

T Tom Frank 34:30

Yeah, no, Newfoundland, and northern territories which I forgot what that's called Yukon. I've been through Yukon BC. Saskatchewan haven't been in a while. No, I have to do Alberta because you came down through Calgary. And Ontario, Quebec. Yeah. Nova Scotia P.E.I and haven't been to Newfoundland. And yeah, I forgot what else is over there. that's

R Rob Mineault 35:00

Wow, pretty good. Also Manitoba.

T Tom Frank 35:05

But yeah, okay, I missed that one.

R Ryan Fleury 35:07

What's the other one up there? Nunavut? northwest territories?

T Tom Frank 35:12

Northwest Territories?

R Rob Mineault 35:15

I mean, that's close enough to make you an honorary Canadian. I was raised here and we probably would have gotten the same score.

T Tom Frank 35:24

So you know a lot more than Americans that can't name the 50 states, let's put it that way.

R Rob Mineault 35:36

It's a big number. Yeah.

T Tom Frank 35:38

And, and I'm in Vermont, and I'd be talking to somebody from California. And they say,

Vermont. What states that in? And then as soon as I say, Ben and Jerry's, oh, you know, Ben and Jerry's. They don't know Vermont. They know Ben and Jerry's though.

 Rob Mineault 35:56

Yeah. Or the Newhart Show? I remember Vermont for that.

 Tom Frank 36:05

And if you're from Vermont, and they said, things like, Oh, the White Mountain Syrup Company. White Mountains are New Hampshire. Vermont has vert in it. Green Mountain. Spelled incorrectly, but it's French for Green Mountain. Green Mountains and the White Mountains. Okay. Well, you know, it's like you and in BC, making fun of people from Newfoundland. And vice versa.

 Rob Mineault 36:35

Yeah, and Quebec, we do enjoy that. And Ontario. Here in BC, we're sort of on the left coast. So we feel we're like the neglected, neglected sibling. So we do enjoy making fun of all the other provinces.

 Tom Frank 36:51

Of course, of course. Yes. And the United States especially.

 Rob Mineault 36:55

Yeah.

 Tom Frank 36:57

But you have but you guys are so nice up here.

 Rob Mineault 37:00

We are, we wait till your back's turned and then we talk about you.

 Tom Frank 37:14

But anyway, CCLVI? Yeah, low vision, no matter where you are.

R

Rob Mineault 37:21

So I want to I want to actually just sort of back up and talk a little bit more about the low vision aspect of it, because I can't emphasize this point enough. I really do feel like low vision is kind of underserviced in terms of a condition. I mean, I would argue that low vision is very rarely used outside of, say, the medical diagnoses. There's a big misconception in the public in terms of vision loss, because really, people really think that you're blind or you're not, they don't often think about people who fall into this gray category that you were talking about earlier. And even when you're in that community, especially initially, it can be very confusing and isolating. And there can be all of these things that come up - I've heard people talk about impostor syndrome, because they feel like they're not really blind but they're not sighted and so they don't really even know how to feel about where they are themselves, let alone other people. Or the fact that people who are low vision can really manifest as almost like an invisible disability. The people around them can maybe not even realize or recognize that they're low vision. Even in the workplace, you can have people that for years will work around being low vision and not even let their workplace know that their low vision, you know, for fear of, you know, whatever, you know, reprisals or whatnot, or even if it's just a personal choice. So, you know, that's why I really think the organization is very important to have people be able to have peer support and to be able to talk through some of these things, because it can be very isolating. I guess the question to you guys is do you have challenges as an organization in terms of educating people that you're out there? Or that you exist? Because I can I can see that it for a lot of people in the general public, they would just refer people to say blindness organizations. What, what kind of challenges do you guys face in terms of of getting the word out there?

T

Tom Frank 39:46

That's what we're doing right now.

C

Christine Chaikin 39:50

Speaking of that, and respond to your question, I've actually been sending out CCLVI flyers. Our Public Relations Committee has put flyers for send to different entities such as low vision specialists, organizations for the blind, vocational rehabilitation state directors, just to name a few. And we've actually gotten a lot of good responses back from that. One of the groups that I did contact and send it to was the Radio Reading Service Directors. So one of them said, they'd like an audio clip of you know what CCLVI, is, another response from Hadley was saying that they put out a workshop called Resources Roundtable. And they were saying they would be glad to mention CCLV.

T

Tom Frank 40:43

And one thing to emphasize, I am, as I said, chair of the Public Relations Committee, but when you say how do we get the word out? I always emphasize to people What can CCLVI do for you? And everybody? Well, if they knew about us, that that would be great. What do we do for them? And that's why we, you know, am I emphasize and recommend everybody tell them, you know, come on game night. And you say game night? Well, we use Zoom. And we just, there's a

bunch of low vision and blind folks that are doing whether it's Jeopardy or whatever games and, and laughing and having fun, like everybody else sighted would do, having fun. And then somebody just might be a feel sorry for themselves and come on with other folks. And that's a sort of a peer support. Come on, have fun. We had a person from Florida that had written and I said, well, I'll contact her. And I called her. And she comes on the chats. And she doesn't say much, because she said, I'm 70, I'm losing my vision. But you know, what am I going to do? And I'm on there, and I'm talking to other low vision folks. They're just having fun. And but, you know, they argue about the same thing I argued about when I had perfect vision, and they have problems with families and kids, and all of that. And well, if you're low vision, no matter where you are, you can, you know, live a full and productive life. Just because you can't see very well doesn't mean that you can't do a lot. And just trying to get that word out, as you say to low vision folks. And I think the statistics are 90% of the folks who are classified as blind or legally blind or impaired have some sort of usable vision, right? And we recommend that people use that vision.

C

Christine Chaikin 43:24

So one of the things that the Public Relations Committee is working on is not only sending out the flyer with different entities on email, but we're also trying to get the CCLVI link and other pages that have resources pages, going back to the CCLVI website. So the more you do that helps. Plus being on different podcasts too.

R

Rob Mineault 43:47

That's right, and expect your numbers to skyrocket now that you've done the AT Banter podcast.

C

Christine Chaikin 43:53

Let me mention really quickly, when you're going to ask me, so does CCLVI have a social media presence? Yes. CCLVI does have a social media presence. So we do have a Facebook page. And that name is Council of Citizens with Low Vision International. And it is also the same on LinkedIn and then again, I will include all of this in the show notes. And then let me also mention really quickly that if anybody is want to become a member of CCLVI you can by going to cclvi.org/join. If you have any questions about membership, you can send an email to cclvimebership@gmail.com.

R

Rob Mineault 44:35

Cross those questions off my off my list. Christine is actually a better host than I am. Our new host Christine. No. So I want to talk to you a little bit about something I noticed on the website. You talk about youth outreach. I know that for other organizations, sometimes getting youth involved into in organizations like this and into advocacy can be very challenging. And for you guys, where I'm sure that a lot of your demographic does tend to skew older because of the whole age related macular degeneration. I'm curious to sort of know what your experience has been in getting youth involved in and if you do find that to be challenging,

T

Tom Frank 45:32

Extremely challenging. If you've got a solution to that problem, please let us know. ACB has ACB Families, specifically who working with families, not just the parents who are visually impaired, but children, parents with children who are visually impaired, and vice versa. What do they do? So it isn't that we're the only ones that deal with low vision. We're sort of advocating for our other affiliates to work with the kids, the youth, and all of them trying to get them involved. And ACB. Whether they join CCLVI, wow, that'd be nice if they did, but just getting them involved in the quote unquote, the blindness community. So they have other people that they can look up to, and reach out for support. Because dating, you know, and we've had some topics that we talk about, well, he gets to us, what do you do for dating? That was difficult, because I started losing my vision when I was 20. You got a single guy, you know, low vision, how do you deal with those? And you say, hi, would you like to go to the movies? When can you pick me up? That doesn't really go well. So, you know, that's where the peer support groups talk about various topics, including that, you know, how do you deal when you're younger, and have low vision? And how parents of kids with low vision understand they're struggling? How do they can help their kids once again.

C

Christine Chaikin 47:38

Yeah, I'm sure one of the other questions you're going to ask us is, so if somebody's interested in receiving the list of CCLVI weekly events>? Well, that is very easy to do, because CCLVI also has a CCLVI-info email list. And what that basically is is an email list where you can get the weekly schedule as well as we mind those of different CCLVI events that are happening. So if anybody wants to subscribe to the email list, you can send an email to CCLVI-info@acblist.org.

T

Tom Frank 48:17

And how do you how do you reach out to younger folks in Canada?

R

Ryan Fleury 48:29

Well, and I was gonna touch on that. So the organization that I'm a part of our, I guess, average demographic is 40 plus as well. And we're in the process of working out strategies to reach out to the younger generation, who seem to be more interested in self advocacy, and maybe aren't aware of the power an organization can have, advocating on your behalf. It's one thing to leave a review in an app. But it's another thing to have a national organization go to bat for you. You know, they've they've been around a lot longer, they may have some advocacy tools in their tool in their tool belt that they can utilize. They may already have contacts or a proven track record with said organization. So I think that's kind of where we need to focus a little bit more on is showing the teens and young adults the power of an organization versus the self advocating which there's a place for it, don't get me wrong. But if you're really going to affect change, I think you need the power of people.



Tom Frank 49:52

Right, because you're quite correct. And that's what an organization does. And and it's hard hard to get people nowadays to join any organization as a group, or social. I mean, we're also social, you know? Because maintaining relationships, low vision, whether you're totally, if you're totally blind, or especially if you're low vision, and you can't drive anymore. You can't say, you know, where when I was single, you know, where do you meet somebody? Well, in a bar, but is she looking at me, I haven't the slightest idea. And I got very good. That's why white cane helps. I remember when I was in California, I was working for the Blinded Veterans Association. And I wanted a map with my magnifying lens, strong magnifying lens, I could read a map. And the motel I was staying, there was a Hertz, Rent-a-Car next door. And I said, Well, maybe they have a map of downtown San Francisco. So I went up to the counter, and I held up my white cane and said, obviously, I'm not here to rent a car. Do you have a little map? And she had a little map. And then I called up later, and I said, wait a second, she looked fairly nice. I wonder if she's single. So I said, well, I look up the Hertz over in Palo Alto and I called, and the guy that answered, said, she's been talking about you all day long. And by feeling sort of self confident, and you're only learn those things by being self confident around other individuals that are dealing with the same issues that you are. That's what what an organization helps you do. Not not just to fight or advocate, but you learn from other folks who have similar experiences.



Christine Chaikin 52:26

Yep.



Rob Mineault 52:28

That's right. Yeah, unfortunately, up here in Canada, we don't have any of the answers either. We we run into the same, issue. I don't know. I'd love to blame social media or Tik Tok and smartphones, completely, but I'm sure there's other there's other factors as well. But yeah, it's tough to get them to get them out and to get them involved in things. You know, I know that when I was 20, I was a meathead as well. So the you know, I'm certain that's part of it. But if we do if we do happen to crack the code, you will be the first to know.



Tom Frank 53:07

Thank you, we appreciate that. If you probably haven't guessed, I tried to use humor, no matter what I deal with. And that's one way I cope. And that right, once again, if you cracked the code, let us know I love to know.



Rob Mineault 53:33

We totally will. Well, listen, guys, thank you so much for coming on and chatting with us. I know we've been dropping plugs through the entire show, which is great, I love but just one last time if people are interested in their organization, learning more about it becoming a member or where can people do that? And are there any criteria that that are necessary in order to become a member?

C

Christine Chaikin 54:36

So basically, since I serve on the membership committee, I will respond to that question. So if you want to become a member, it is \$15 at large, you could pay by cheque. If you pay online it is \$16 if you become a member at large. It is an online form and if anybody's interested in joining, you can go to cclvi.org/join. And then if you have any questions regarding member regarding how to join CCLVI as a at large member or as one of the five of the CCLVI Chapter Affiliates, you can send an email to CCLVImembership@gmail.com.

R

Rob Mineault 55:14

Excellent. Well, listen, guys, thank you once again, for coming on and stay in touch.

C

Christine Chaikin 55:16

Well, thank you very much for the opportunity for letting us be on and get the information, get the word out more about CCLVI, we really appreciate it.

R

Rob Mineault 55:30

Awesome.

T

Tom Frank 55:31

Thank you very, very much. Okay. Take care. Thanks.

R

Rob Mineault 55:37

Very cool. Yeah, I like this organization a lot. I do really feel like a low vision is kind of underserved as a as a community. So it's nice to see. And I don't know of any other organization like this, that that specifically services low vision, do you guys know of any?

R

Ryan Fleury 55:54

Off the top of my head?

R

Rob Mineault 55:56

Everything's blindness, right? Like everything vision really centered around blindness. Yeah, I mean, I don't know. I feel like low vision does have a specific set of of unique challenges.

R

Ryan Fleury 56:11

Well it does. Yeah. And as Tom said, you know, the blind, those of us who are totally blind are a minority for sure. Right. Low Vision is a much, much bigger segment of the population.

R

Rob Mineault 56:22

Well, and anybody who's going through a degenerative eye condition, they're gonna go through that low vision period first. That's, their entry point, even if they do eventually lose their sight, that's their entry point into blindness. So like having support front loaded into something like a low vision organization that can help you and help that transition. Anything else? Any final thoughts?

S

Steve Barclay 56:49

No, nothing for me.

R

Rob Mineault 56:51

Hey Ryan.

R

Ryan Fleury 56:53

Yeah, Rob?

R

Rob Mineault 56:55

Where can people find us?

R

Ryan Fleury 56:57

www.atbanter.com Hey, they can also drop us an email if they so desire cobbell@atbanter.com. That sounded really dainty. That was like a dainty cowbell strike. We have an episode coming up the end of the month that we'll be talking all about that. Stay tuned.

R

Rob Mineault 57:21

About the cowbell?

R

Ryan Fleury 57:23

Why I may whiff on the cowbell.

R

Rob Mineault 57:26

Oh, wow, we're having a whole episode based on that?

R

Ryan Fleury 57:30

It's actually a condition, I think it's called aphasia. Take a look your invites in your calendar, aphasia.

R

Rob Mineault 57:44

Really? Yeah. Okay. Well, listen, I look forward to that.

R

Ryan Fleury 57:47

We have a guest brought to us from Ted Drake from Intuit.

R

Rob Mineault 57:52

Ryan got so sick of us to have us teasing him about him missing on the cowbell. Now we're going to be assholes.

R

Ryan Fleury 58:05

That's never stopped you before.

R

Rob Mineault 58:10

Yeah, Pinball. All right. Yep. Hey, where else can they find us? Anybody?

S

Steve Barclay 58:19

Oh, I'd go with Ryan on that one. Because social media doesn't exist.

R

Ryan Fleury 58:24

They can find us at Facebook. They can find us on x. They can find us on Mastodon or they can find us at Canadian Assistive Technology www.caasstch.com

R Rob Mineault 58:37

Yeah, that's a good place to find us.

R Ryan Fleury 58:39

That is.

R Rob Mineault 58:41

Hey, a side note. Did you guys - I mean, obviously you didn't see it, we didn't we didn't get to see the Eclipse. But did you follow that?

S Steve Barclay 58:54

Yeah. I read an article that said that immediately following the eclipse the number of searches for "Why do my eyes hurt" spiked on Google.

R Ryan Fleury 59:07

Are you serious?

R Rob Mineault 59:08

I was just gonna say that. I read that same article.

R Ryan Fleury 59:11

Trump supporters.

R Rob Mineault 59:19

It's absolutely hilarious. I love it. Boy. All right. Let's get out of here. All right, that is going to about do it for us this week. Big thanks, of course to Tom and Christine for joining us and we will see everybody next week.

S Steve Barclay 59:46

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